



## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Agency for Healthcare Research and Quality

#### Supplemental Evidence and Data Request on Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs

**AGENCY:** Agency for Healthcare Research and Quality (AHRQ), HHS.

**ACTION:** Request for Supplemental Evidence and Data Submissions.

**SUMMARY:** The Agency for Healthcare Research and Quality (AHRQ) is seeking scientific information submissions from the public. Scientific information is being solicited to inform our review on *Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs*, which is currently being conducted by the AHRQ's Evidence-based Practice Centers (EPC) Program. Access to published and unpublished pertinent scientific information will improve the quality of this review.

**DATES:** *Submission Deadline* on or before [INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER].

#### ADDRESSES:

*E-mail submissions:* [epc@ahrq.hhs.gov](mailto:epc@ahrq.hhs.gov)

*Print submissions:*

Mailing Address:

Center for Evidence and Practice Improvement

Agency for Healthcare Research and Quality

ATTN: EPC SEADs Coordinator

5600 Fishers Lane

Mail Stop 06E53A

Rockville, MD 20857

Shipping Address (FedEx, UPS, etc.):

Center for Evidence and Practice Improvement

Agency for Healthcare Research and Quality

ATTN: EPC SEADs Coordinator

5600 Fishers Lane

Mail Stop 06E77D

Rockville, MD 20857

**FOR FURTHER INFORMATION CONTACT:**

Jenae Benms, Telephone: 301-427-1496 or Email: [epc@ahrq.hhs.gov](mailto:epc@ahrq.hhs.gov).

**SUPPLEMENTARY INFORMATION:**

The Agency for Healthcare Research and Quality has commissioned the Evidence-based Practice Centers (EPC) Program to complete a review of the evidence for *Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs*. AHRQ is conducting this systematic review pursuant to Section 902 of the Public Health Service Act, 42 U.S.C. 299a.

The EPC Program is dedicated to identifying as many studies as possible that are relevant to the questions for each of its reviews. In order to do so, we are supplementing the usual manual and electronic database searches of the literature by requesting information from the public (e.g., details of studies conducted). We are looking for studies that report on *Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs*, including those that describe adverse events. The entire research protocol is available online at: <https://effectivehealthcare.ahrq.gov/products/transitions-care-pediatric-adult/protocol>

This is to notify the public that the EPC Program would find the following information on *Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs* helpful:

- A list of completed studies that your organization has sponsored for this indication. In the list, please *indicate whether results are available on ClinicalTrials.gov along with the ClinicalTrials.gov trial number*.
  - *For completed studies that do not have results on ClinicalTrials.gov*, a summary, including the following elements: study number, study period, design, methodology, indication and diagnosis, proper use instructions, inclusion and exclusion criteria, primary and secondary outcomes, baseline characteristics, number of patients screened /eligible /enrolled /lost to follow-up /withdrawn /analyzed, effectiveness/efficacy, and safety results.
- *A list of ongoing studies that your organization has sponsored for this indication*. In the list, please provide the ClinicalTrials.gov trial number or, if the trial is not registered, the protocol for the study including a study number, the study period, design, methodology, indication and diagnosis, proper use instructions, inclusion and exclusion criteria, and primary and secondary outcomes.

- Description of whether the above studies constitute *ALL Phase II and above clinical trials* sponsored by your organization for this indication and an index outlining the relevant information in each submitted file.

Your contribution is very beneficial to the Program. Materials submitted must be publicly available or able to be made public. Materials that are considered confidential; marketing materials; study types not included in the review; or information on indications not included in the review cannot be used by the EPC Program. This is a voluntary request for information, and all costs for complying with this request must be borne by the submitter.

The draft of this review will be posted on AHRQ's EPC Program website and available for public comment for a period of 4 weeks. If you would like to be notified when the draft is posted, please sign up for the e-mail list at: <https://www.effectivehealthcare.ahrq.gov/email-updates>.

*The systematic review will answer the following questions. This information is provided as background. AHRQ is not requesting that the public provide answers to these questions.*

### **Key Questions (KQs)**

- **KQ1:** What are the effectiveness, comparative effectiveness, harms, and costs of **care interventions for transition** from pediatric to adult medical care services, including primary care, for children with special healthcare needs and their families/caregivers?
  - **KQ1a:** How do outcomes vary by intervention characteristics or components?
  - **KQ1b:** How do outcomes vary by patient/caregiver or provider characteristics or setting?
  - **KQ1c:** What are the barriers and facilitators to effective transitions?
  - **KQ1d:** What are the gaps in evidence for the effectiveness of the interventions?
- **KQ2:** What are the effectiveness, comparative effectiveness, harms, and costs of **implementation strategies for care interventions for transition**, including provider-related training?
  - **KQ2a:** How do outcomes vary by intervention characteristics or components?
  - **KQ2b:** How do outcomes vary by patient/caregiver or provider characteristics or setting?
  - **KQ2c:** What are the barriers and facilitators to effective implementation?
  - **KQ2d:** What are the gaps in evidence for the effectiveness of the interventions?
- **KQ3:** What is the effectiveness, comparative effectiveness, harms, and costs of **tools to facilitate communication between pediatric and adult providers** for care transitions

from pediatric to adult medical care for children with special healthcare needs and their families/caregivers?

- **KQ3a:** How do outcomes vary by intervention characteristics or components?
- **KQ3b:** How do outcomes vary by patient/caregiver or provider characteristics or setting?
- **KQ3c:** What are the barriers and facilitators to effective tools to facilitate communication?
- **KQ3d:** What are the gaps in evidence for the effectiveness of the interventions?

## Contextual Questions

In addition to the identified key questions, the report will include a mixed-methods evaluation of the contexts in which interventions for transitioning children with special healthcare needs from pediatric to adult services are developed and used. **Contextual** questions to be evaluated include:

1. How is effectiveness defined and measured for transitions of care from pediatric to adult services for children with special healthcare needs?
2. What transition care training and other implementation strategies are available to prepare pediatric medical providers (e.g., pediatricians and other specialists) and adult medical providers (e.g., primary care providers, nurse practitioners, physician assistants) for transitioning children with special healthcare needs to adult care?
3. What training is available for linguistic- and culturally competent care?
4. What transition care training and other implementation strategies are available to prepare pediatric patients and their families for transitioning children with special healthcare needs to adult care?
5. What care interventions including primary care have been used for transition from pediatric to adult medical care for children with special healthcare needs?
6. What strategies have been proposed to increase availability of adult care providers for people transitioning from pediatric to adult care?

## PICOTS (Populations, Interventions, Comparators, Outcomes, Timing, Settings)

PICOT	KQ1: Benefits and Harms of Care Intervention	KQ2: Implementation Strategies	KQ3: Communication Tools
<b>Population</b>	Adolescents and young adults (diagnosed with cancer or other special healthcare condition before 21 years old) with a	Multi-disciplinary care providers (e.g. primary care/ family medicine physicians, specialty	Multi-disciplinary care providers (e.g. primary care/family medicine physicians, specialty

	<p>chronic physical or mental illness or physical, intellectual, or developmental disability, also including parents and/or care givers.</p> <p>Patient subgroups: disease condition (including cancer), age of diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, adverse childhood events</p> <p>Provider subgroups: age, sex, race/ethnicity, education, socioeconomic status, specialty, care setting</p>	<p>care physicians, nurse practitioners, physician assistant, etc.) caring for adolescents and young adults with a special healthcare need</p> <p>Patient subgroups: disease condition (including cancer), age of diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, adverse childhood events</p> <p>Provider subgroups: age, sex, race/ethnicity, education, socioeconomic status, specialty, care setting</p>	<p>care physicians, nurse practitioners, physician assistant, etc.) providers caring for adolescents and young adults with a special need</p> <p>Patient subgroups: disease condition (including cancer), age of diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, adverse childhood events</p> <p>Provider subgroups: age, sex, race/ethnicity, education, socioeconomic status, specialty, care setting</p>
<b>Intervention</b>	<p>Intervention related to the care transition from pediatric to adult medical care (e.g., any single or multi-component intervention that addresses the Six Core Elements of healthcare transition such as educational materials, patient care documents, processes, etc. There are not widely established neat packages of intervention components; interventions vary widely in their components, structure, and processes.) No healthcare transition intervention is explicitly excluded. However, transition interventions that address the full spectrum of transition to adult life, such as transition to independent living from foster care or among people with developmental disabilities, will be excluded.</p>	<p>Implementation strategies, including training (e.g., any single or multi-component intervention that addresses implementing the Six Core Elements of healthcare transition such as trainings)</p>	<p>Tools for provider communication (e.g., any single or multi-component intervention that addresses communication that supports the Six Core Elements of healthcare transition such as patient care documents)</p>
<b>Comparators</b>	<p>Comparator required, but no exclusion based on comparator type</p>	<p>Comparator required, but no exclusion based on comparator type</p>	<p>Comparator required, but no exclusion based on comparator type</p>

<b>Outcomes</b>	<ul style="list-style-type: none"> <li>○ Transition readiness (e.g., patient, family, provider, and system level)</li> <li>○ Quality of life</li> <li>○ Mortality</li> <li>○ Morbidity</li> <li>○ Disease-specific clinical outcomes</li> <li>○ Wellness visits/screenings (e.g., depression, anxiety, STIs, other risk and resiliency factors such as alcohol use, substance abuse, violence)</li> <li>○ Treatment or care adherence</li> <li>○ Engagement in care (e.g., no shows, time between providers, satisfaction, loss to follow-up, time between leaving pediatric setting to going to adult)</li> <li>○ Satisfaction (patient and family)</li> <li>○ Family caregiver outcomes</li> <li>○ Harms</li> <li>○ Unintended consequences (e.g., ethics of transition)</li> <li>○ Psychosocial (e.g., social-emotional, mental health, etc.)</li> <li>○ Insurance</li> <li>○ Cost</li> <li>○ Resource utilization (ER visit, hospitalization, length of stay)</li> </ul>	<ul style="list-style-type: none"> <li>○ Intervention <ul style="list-style-type: none"> <li>▪ Adoption</li> <li>▪ Fidelity</li> <li>▪ Sustainability</li> <li>▪ Feasibility</li> <li>▪ Acceptability</li> </ul> </li> <li>○ Satisfaction (physician and other formal caregiver)</li> <li>○ Quality of life</li> <li>○ Mortality</li> <li>○ Morbidity</li> <li>○ Disease-specific clinical outcomes</li> <li>○ Family Caregiver outcomes</li> <li>○ Harms</li> <li>○ Unintended consequences (e.g., ethics of transition)</li> <li>○ Cost of implementation</li> <li>○ Insurance</li> </ul>	<ul style="list-style-type: none"> <li>○ Transition readiness</li> <li>○ Quality of life</li> <li>○ Mortality</li> <li>○ Morbidity</li> <li>○ Disease-specific clinical outcomes</li> <li>○ Treatment or care adherence</li> <li>○ Engagement in care (e.g., no shows, time between providers, satisfaction, loss to follow-up, time between leaving pediatric setting to going to adult)</li> <li>○ Satisfaction (patient and family)</li> <li>○ Family Caregiver outcomes</li> <li>○ Harms</li> <li>○ Unintended consequences (e.g., ethics of transition)</li> <li>○ Insurance</li> <li>○ Cost</li> <li>○ Resource utilization (ER visit, hospitalization, length of stay)</li> </ul>
<b>Timing</b>	At least 6 months post transition for tests of interventions. No exclusions for qualitative or mixed studies for barriers and facilitators subquestion.	At least 6 months for tests of interventions. No exclusions for qualitative or mixed studies for barriers and facilitators subquestion.	At least 6 months for tests of interventions. No exclusions for qualitative or mixed studies for barriers and facilitators subquestion.
<b>Setting</b>	All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth)	All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth)	All settings (e.g., primary care, specialty care, schools, rural, resource limited settings, and telehealth)

Dated: November 27, 2020.

**Marquita Cullom,**  
Associate Director.

